



NATIONAL FAMILY CAREGIVERS ASSOCIATION

10400 Connecticut Avenue, Suite 500

Kensington, MD 20895-3944

June 30, 2004

The Honorable Edward J. Markey
The Honorable Christopher H. Smith
U.S. House of Representatives
Washington, DC 20515

Dear Congressmen Markey and Smith:

The National Family Caregivers Association (NFCA) is a grassroots organization that educates, supports, empowers and speaks up for our nation's more than 50 million family caregivers who provide care for loved ones with chronic disease or disability. We know first hand the difficulties faced by family caregivers. For that reason I writing in strong support of your legislation, ***"The Ronald Reagan Alzheimer's Breakthrough Act" (HR 4595)***.

The bill recognizes the urgent need to focus more attention on finding a cure for Alzheimer's disease while simultaneously educating the public about prevention techniques that can maintain our brains as we age. Alzheimer's disease has become what cancer was in the past – the most dreaded of all diseases.

We are especially supportive of those provisions that focus on family caregivers, those who care for Alzheimer's patients and also those who care for loved ones with other conditions such as Parkinson's cerebral palsy, and diabetes. The research on family caregiving is very clear. Family caregivers suffer from clinical depression, back problems, sleep disorders and in some cases higher mortality rates than non-caregivers. In addition caregiving families suffer financially; on average spending more than 11 percent of income on out-of-pocket medical expenses. This is two and a half times more than is spent by typical American families. Add to this the fact that caregiving families have lower incomes than average Americans and it is clear that caregiving families need physical, emotional, and financial assistance.

The tax provisions of HR 4595 will help alleviate some of this financial burden. When you realize that adult diapers alone can cost as much as \$1,500 a year, it is not hard to see how quickly expenses can add up and why the proposed \$3,000 tax credit is needed.

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Congressman Edward Markey
Congressman Christopher Smith

Page 2

Expanding resources for the National Family Caregiver Support Program will enable Area Agencies on Aging to help thousand more family caregivers. In some cases current funding levels have provided as little as \$19,000 to an agency serving five counties. The program is the only federal effort specifically designed to support family caregivers. It is providing much needed information and referral services, decision support, and more to caregivers of the elderly. Doubling its initial funding will enhance the efforts already underway.

With research showing that respite care is of such prime importance to the health and well being of family caregivers, and that it cuts down on costly out-of-home placements, we are also particularly pleased that the legislation includes the full text of the Senate-passed bill, the Lifespan Respite Care Act (S. 538). This bill recognizes that caregiving can and does occur anywhere within the life cycle. There are millions of families caring for children with special needs, millions more caring for adults from ages 20 – 60, and the largest number caring for seniors. The Lifespan Respite Care Act will provide a coordinated system of respite care for all of them, train respite workers and dramatically improve access to quality respite for family caregivers regardless of their loved one's age, diagnosis or Medicaid status.

For all of these reasons we stand ready to assist you with the passage of this important legislation that deals with so many aspects of caregivers' lives and addresses our most fervent wish to find the causes and cures of devastating diseases, of which Alzheimer's is quite possibly the most horrible.

If you need more information, please don't hesitate to contact me.

Sincerely,



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President/Co-founder

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